network
NETWORK 35 MARCH 2013

Treating hepatitis C in patients with established cirrhosis

Steve Brinksman discusses encouraging advances in treatment of hepatitis C for patients who have liver cirrhosis. Ed.

In the UK liver disease is the fastest rising major cause of mortality and typically causes death at a younger age than the other major conditions[1].

Viral hepatitis is a significant cause of liver related morbidity and mortality as over time it causes inflammation and then fibrotic changes that can lead to cirrhosis and subsequent decompensated liver disease and an increased risk of developing hepatocellular carcinoma [HCC].

> *"despite the large strides that have been made in terms of screening and the development of treatments that can be curative there is a large reservoir of people who have hepatitis C but are unaware of the fact"*

It has been estimated that approximately 50% of the infected population needs to be treated to have any discernible effect on morbidity and mortality [2] a figure that here in the UK we are currently well short of achieving. Over the next few years if current trends continue there will be approximately 3000 cases per year of decompensated liver disease or HCC from hepatitis

1 Office for National Statistics (2008) Health Service Quarterly, Winter 2008, No. 40 p59-60

2 Hepatitis C Trust (2009)An audit of Strategic Health Authority hepatitis C governance

...continued overleaf

In this issue

We hope you enjoy this edition.

Editor

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C against a steady number of 700 liver transplants per year. It is therefore vital that treatment paradigms are implemented to deliver the most effective outcomes.

The hepatitis C virus was first identified in 1987[2] and despite the large strides that have been made in terms of screening and the development of treatments that can be curative there is a large reservoir of people who have hepatitis C but are unaware of the fact. These patients may only present when they already have established cirrhosis. Treatment aimed at curing hepatitis C in this group is more difficult as there is an increased incidence of adverse reactions [3].

3 Houghton M (2009) "The long and winding road leading to the identification of the hepatitis C virus". *Journel of Hepatology* 51 (5): 939–48.

Editorial

This edition of Network comes to you at a time of great change in the structure of commissioning, with Public Health Directors settling into their roles within local councils to take on responsibility for commissioning drug and alcohol services via health and wellbeing boards. As ever, change brings both challenges and opportunities and SMMGP together with the RCGP have issued a joint paper ***Primary care drug and alcohol treatment: commissioning and provision against a backdrop of localism*** to support primary care to navigate the new territory. To see the paper please visit www.smmgp.org.uk

This edition of Network has as usual a mixture of clinical and policy articles from the field. As the outgoing Chief Executive Officer of the National Treatment Agency, **Paul Hayes** provides a fascinating insight into drug policy over the years on **page 8**, and **Chris Ford** discusses the importance of the role of doctors in developing healthy drug policies **on page 13**. **Steve Brinksman** covers treatment for hepatitis C in those with liver damage on the front page, and **Julia Brown** highlights the important issue of foetal alcohol spectrum disorders on **page 6**.

You will be pleased to learn you can **save the date for SMMGP's Development of drug and alcohol treatment in primary care conference *Working with the individual in a public health framework: how do we measure up?*** on the **24th October 2013 in Manchester.** For more information visit **www.smmgp.org.uk**

Finally, don't forget to book your place on the **RCGP 18th National Conference Working with drug and alcohol problems in primary care in Birmingham on May 16th and 17th.** The theme of this year's conference **is Joining the dots: public health and social inclusion. For more information visit http://www.rcgp.org.uk/courses-and-events/managing-drug-and-alcohol-problems.aspx**

Enjoy this issue!

Kate Halliday

Editor

Cirrhosis is histologically the end stage of a number of processes that cause liver inflammation and subsequent fibrosis. It is defined as a diffuse hepatic process characterised by fibrosis and the conversion of normal liver architecture into structurally abnormal nodules. It can be categorised using the Child-Pugh classification with a higher score being associated with a worse prognosis. The gold standard assessment of cirrhosis is via a liver biopsy as it accurately determines the disease severity through a system of scoring for both fibrosis and inflammation. This procedure is not without risk and increasingly transient elastography (fibroscan) is used as measurement of likely fibrosis, although it is unable to provide detail around severity other than suggesting mild or severe and is less accurate in the obese patient.

The transition from compensated to decompensated cirrhosis can occur for a variety of reasons and is associated with a range of clinical signs such as ascities, oesophageal varicies, encephalopathy and an increased clotting time; these are all associated with a much worse prognosis.

Multiple studies have looked at the use of triple therapy (pegylated interferon, ribavirin and either telaprevir or boceprevir); many of these trials have had very few patients with cirrhosis included or have actively excluded them. As a result the UK consensus guidelines [4] state, "The presence of advanced hepatic fibrosis or cirrhosis is a major risk factor for treatment failure". This situation is more pronounced in those who have been non-responders to previous anti-viral therapy. Within the REALISE [5] study the sustained viral response (SVR) rate in this group was still only 22–28%. Furthermore, relapse rates were high (25–27%) with even higher levels of virological failure (47–57%), predominantly due to the emergence of resistant variants.

The CUPIC study [6] was set up specifically to look at triple therapy in patients with established cirrhosis. The preliminary findings were presented in 2012. The study looked at triple therapy regimes with two subsets [telaprevir or boceprevir]. Although there were some differences between the two groups the findings for both were broadly similar.

Between 40 - 50% of those treated experienced serious adverse events during the study and 7 - 15% had to leave the study prematurely because of this.

About 2% of study entrants died, with the commonest causes of death being:

- severe bacterial infections
- pneumonia
- internal bleeding
- neurological complications.

Other significant complications were common such as:

- severe infections – 9%

4 Lee SS, Roberts SK, et al (2012) "Safety of peginterferon alfa-2a plus ribavirin in a large multinational cohort of chronic hepatitis C patients". Liver Int 2012 Sep;32(8):1270-7.

5 Ramachandran P et all (2012) UK consensus guidelines for the use of the protease inhibitors boceprevir and telaprevir in genotype 1 chronic hepatitis C infected patients. Aliment Pharmacol Ther 2012; 35: 647-662

6 Zeuzem S, Andreone P, Pol S, et al. (2011) Telaprevir for retreatment of HCV infection. N Engl J Med 2011; 364: 2417 –28.

- severe rash – 8%
- severe weakness – 5%
- complications from deteriorating liver function – 4%
- severe or life-threatening anemia occurred in 10%
- between half and two thirds of had to be given EPO (erythropoietin)
- over 10% had blood transfusions
- 12% of patients had a significant enough fall in their platelet levels.

Triple therapy with a protease inhibitor was very effective at suppressing hepatitis C virus (HCV) levels, even in those who were very ill and had a history of a poor response / high relapse rate with peginterferon and ribavirin. By the fourth week of therapy in CUPIC, just over 50% of those still in treatment had undetectable HCV levels in their blood. Moreover by the sixteenth week of the study, over 70% had undetectable HCV levels. This finding shows that even very ill people can benefit from triple therapy. Long-term monitoring is continuing to assess rates of cure and relapse following triple therapy.

These preliminary findings suggest that whilst there is evidence of good virological response in those with cirrhosis the safety profile of treatment is poorer with an increased risk of adverse events and an increased dropout rate from treatment compared with the results from trials that had no or a minimal number of cirrhotic patients in them. Their current advice is that the decision to treat someone with established cirrhosis should be taken with caution and they should be more closely monitored during treatment.

> ***"the number of patients with advanced fibrosis that need to be treated to prevent a liver related mortality was 18 which is significantly lower than for those with less marked liver disease in which 60 treatments are required"***

It would therefore appear that treatment of the more ill patient is fraught with difficulty and given the cost of a course of treatment it may seem illogical to treat this group; however despite this treatment modeling[7] has shown that over a 5 year period the number of patients with advanced fibrosis that need to be treated to prevent a liver related mortality was 18 which is significantly lower than for those with less marked liver disease in which 60 treatments are required. Stopping treatment in those with a poor early response could reduce the number of adverse events; however if this rule was followed there was also a significant loss of benefit with approximately a third less liver deaths prevented. The authors conclude that subjects with advanced fibrosis should be prioritised for triple therapy on the basis of need and that treatment if tolerated should be continued regardless of initial viral response.

A review of the available evidence published in Hepatitis Monthly in 2012[8] concluded that patients with HCV related compensated cirrhosis (Child-Pugh class A) are the group most likely to benefit from viral clearance. However it was suggested that those with decompensated disease (Child-Pugh class C) should only be considered for treatment if on a transplantation waiting list due the risk of spontaneous bacterial peritonitis and other severe adverse reactions. It is suggested that further evidence is needed to recommend treating those with an intermediate picture (Child-Pugh class B].

The evidence supporting treatment in those with compensated cirrhosis shows a reduction in the incidence not only of hepatocellular carcinoma[9] but also a reduction in other liver related complications[10]. It is postulated that this may be due to the histological regression from cirrhosis reported in many patients who achieve a sustained viral response. Despite this these patients will require ongoing monitoring as although significantly reduced there is still a risk of progression to HCC.

There seems little doubt that using triple therapy in patients with less advanced fibrosis is more likely to result in a sustained virological response and these patients are likely to have a longer mean survival time; however that greater survival time reflects the fact they are a younger and healthier subset. In fact more patients from this group need to be treated to prevent a liver related death. Identification of those with more advanced fibrosis up to and including compensated cirrhosis and provision of treatment to this group is currently the most cost effective approach albeit that the current treatment guidelines would also support treatment of those with less advanced disease. Patients with more advanced cirrhosis are at greater risk from undertaking triple therapy although they may well benefit if they were able to achieve SVR. The decision to start treatment needs to be looked at on an individual case basis with an informed decision made by the patient.

Further reading

Bruno S, Stroffolini T (2007) Sustained virological response to interferon-alpha is associated with improved outcome in HCV-related cirrhosis: a retrospective study. Hepatology. 2007;45(3):579–87.

Steve Brinksman, SMMGP Clinical Lead

7 Hezode C (2012) Safety of Telaprevir or Boceprevir in combination with Peginterferon alfa/ribavirin, in cirrhotic non-responders first results of the French early access programme (ANRS CO20-CUPIC) Presented EASL 47th Annual Meeting Barcelona April 2012

8 Rowe IA, Houlihan DD (2012) Despite poor interferon response in advanced hepatitis C virus infection, models of protease inhibitor treatment predict maximum treatment benefit. Aliment Pharmacol Ther. 2012 Oct;36(7):670-9

9 D'Ambrosio R, Aghemo A. (2012) Treatment of Patients With HCV Related Cirrhosis: Many Rewards With Very Few Risks. Hepat Mon. June; 12(6): 361–368.

10 Yoshida H, Shiratori Y (1999) Interferon therapy reduces the risk for hepatocellular carcinoma: national surveillance program of cirrhotic and non cirrhotic patients with chronic hepatitis C in Japan. Ann Intern Med. 1999;131:174–81.

Jim Orford and his colleagues highlight the difficulties that families of people with drug and alcohol problems can face, and outline the 5-Step-Method to support them within a primary care setting. Ed.

Reaching primary care patients who are affected by their relatives' alcohol, drug (or gambling) problems

Our group has spent a number of years collecting information about the impact that addiction problems have on other family members. Much of this impact is directly health-related. Our interview data are full of references by affected family members' (AFMs), as we call them, to their general poor health, feelings of anxiety and depression, disturbances of sleeping and eating, an increase or instability in their own use of substances including tobacco and prescribed medication, as well as to symptoms of physical illness such as anaemia, headaches, back pain, hypertension, asthma, palpitations, migraines and diarrhoea. The presence of these symptoms and high level of use of primary care is also evident from other large research studies, for example in the United States [1]. This is a large group of highly stressed people. What strikes us is how the nature of that stress and one of the main underlying causes of their ill-health mostly go unrecognised.

We believe that general practice is the setting where much of this hidden harm for AFMs can be detected and responded to. In fact, it is hard to imagine where else that could happen (except perhaps at school in the case of children and young people). However, our experience makes us believe that the particular circumstances of AFMs still frequently remain invisible in general practice and that their special needs are therefore often not addressed. Part of the reason for that, we think, has been the absence of a way of understanding the health-related experience of AFMs (a suitable model) and a way of responding which can be used at the primary care level (a suitable method). As a result of our programme of research we have developed the Stress-Strain-Coping-Support (SSCS) Model and the 5-Step Method in order to fill those gaps. We shall say more about the latter shortly, but the SSCS Model is the basis for it and is therefore crucial. Some previous models of addiction and the family have assumed family pathology – wives who drive their husbands to drink, parents who have neglected their children who then misuse drugs, family members who are co-dependent. The SSCS Model makes the very different assumptions that AFMs are a cross-section of ordinary people who are struggling to find ways to cope with the stress of having an addiction problem in the family, often without much support or guidance, and who as a result are at high risk for a variety of mental and physical health problems. The 5-Step Method is based on that model. The five steps are as follows:

Step 1: *Listen, reassure and explore concerns*

This includes: allowing family members to describe the situation and its impact; identifying relevant stresses; identifying the need for further information; communicating realistic optimism; and identifying the need for future contacts. We have found the first step to be one of the most important since AFMs will rarely have had the chance to talk about what they have been experiencing and how stressful it is to someone who is prepared to listen, to take what the family member says seriously, and not to be judgemental or to jump in with advice.

Step 2: *Provide relevant, specific information*

This step aims to: increase knowledge and understanding; and to reduce stress arising from a lack of knowledge or misconceptions. Some of what family members find useful consists of objective and factual information, for example about types of drug and their effects or about units of alcohol. But some of it is about questions regarding the nature of dependence; for example, why relatives seem to find it so difficult to control substance use. Family members often struggle to understand their relatives' behaviour, which may appear so unreasonable, selfish and destructive to the family.

Step 3: *Explore how the family member is dealing with the situation*

At this step current ways of responding are identified and their advantages and disadvantages discussed and alternative ways are explored and their potential advantages and disadvantages are also discussed. Having someone in the family with an addiction problem creates coping dilemmas for family members, ranging from whether to take more control of family finances to struggling with the decision over whether to separate. These are very individual depending upon the family and its circumstances, but there are a number of broad common themes. These dilemmas often revolve around questions of whether to engage in trying to control the problem or to protect oneself and the family against it (standing up to it), to show tolerance or acceptance (putting up with it) or to try and put some distance between oneself and the problem (withdrawing and gaining independence). At this important step, it is usually not so much a matter of giving advice but rather one of giving the family member time to reflect on the pros and cons of current and alternative ways of coping. Many family members find it helpful to know about these three broad themes and to see how their ways of managing fit into them.

Step 4: *Discuss social support*

The aims of this step are: to improve communication within the family; to facilitate a unified and coherent family approach to the problem; and to explore potential new sources of support for the family member. We recommend drawing a social network diagram as a useful aid. Because family members are often very isolated,

1 Ray, G., Mertens, J. and Weisner, C. (2007). The excess medical cost and health problems of family members of persons diagnosed with alcohol or drug problems. *Medical Care*, 45 (2): 116–122.

this fourth step, which can help AFMs identify sources of emotional or practical help, or of information, which they might not have thought of before, is often found to be very valuable.

Step 5: *Discuss and explore further needs*

Finally, at the fifth step, possible options for further help for the family member are discussed; and contact between the family member and other sources of specialist help are facilitated. We believe that the strength of the 5-Step Method lies in the fact that it is designed for family members in their own right and is focused on their experiences of having a close relative with an addiction problem, their dilemmas in deciding how to cope, and the information and support which they need themselves. The focus is on them as people coping with addiction in their families. It is not personal psychotherapy because the focus is on dealing with a current difficulty which is highly stressful and not on the family member's own background and personality. Nor is it marital or family therapy since it is for the family member in her or his own right. However, at the fifth stage there is an opportunity to consider whether something else is necessary, including, if appropriate, a discussion of what the substance using relative may need in the way of help and how that might be facilitated.

What can the primary health care team do?

But can this be done in the general practice setting? We always intended that it should be. In fact its origins go back to discussions at the World Health Organisation nearly 25 years ago about finding flexible ways to deliver help to AFMs in primary care. Although the components of the method are described in terms of five distinct steps, in practice much can be done in the course of a single meeting if that is necessary. Delivering just the first step can be very powerful because it can represent the new experience for a family member of talking openly about something which previously has been secret. Just being told that their experiences are not unusual but are shared by many others can be very uplifting for family members. Delivering at least steps one and two over one or two sessions is something that most members of the team should be in a position to do. There is a self-help handbook which accompanies the method and we intend to make a web-based version available during 2013, so shortage of time for face-to-face contact need not be an insuperable barrier.

In England we have carried out two research studies in which volunteer GPs, practice nurses and health visitors were trained to deliver the 5-Step Method. Two key outcomes for family members were assessed and found to be significantly affected at 3 and 12 month follow-up: reductions in engaged and tolerant ways of coping; and a reduction in common symptoms of mental and physical ill-health. We also assessed, before and after, the attitudes of the primary health care workers towards working with family members affected by addiction. We found significant positive changes, particularly in their level of confidence about working with AFMs.

When we discussed with family members how the intervention in general practice had helped them, if it had, the following four types of change were talked about most frequently: an increasing independence or distance from the relative's problem drinking or drug-taking, most commonly referred to in terms of an increased focus on oneself and on one's own needs; being more assertive, by communicating more directly with the relative than previously, by being more directive in arranging alternative activities, or by being firmer in maintaining a course of action; becoming less emotional in interactions with the relative; and understanding more about the relative's drinking or drug-taking and realising better the links between the relative's drinking or drug-taking and the AFM's own physical or mental health.

In a third study we tried to take this work further by providing all the clinical staff of a single practice with brief training in the 5-Step Method and support over a period of 18 months. The practice served around 7000 patients, and we estimated that the number of adult AFMs might be in the region of 175 (with perhaps 60 affected children as well). The practice GPs estimated between them that they had seen approximately 65 AFMs in a period of 12 months during the project, of whom only about half were identified as suitable for various reasons.

> ***"Just being told that their experiences are not unusual but are shared by many others can be very uplifting for family members"***

We believe we have demonstrated that the 5-Step Method can be delivered in general practice but it is clear that questions remain. Families where there are already identified addiction problems frequently have complex problems, often involving other health and social care agencies; it may then be concluded – we believe wrongly – that it is inappropriate to apply a focused intervention such as 5-Step. Identifying less obvious cases can be very difficult; but members of the practice we worked with in our third project believed that identification can be improved by a combination of asking the right questions and recognising the signs. A number of the GPs saw the work involved as being too time-consuming and constituting a specialism beyond their role. Because of the flexible nature of the 5-Step Method, we had always envisaged that it could be delivered by a range of different professionals, but in our experience not all nurses, nor all practices, have seen this as work which practice nurses can undertake. Of course things change: primary care, and different members of the primary care team, are increasingly involved in the management of those with drug problems and in screening for and providing brief interventions for unhealthy drinking, for example.

Despite the challenges, nearly all the GPs and their colleagues who have taken part in our studies have agreed that general practice is the right place to identify patients whose health is being affected by living with a relative who has an addiction problem. The problem is one of high prevalence, such patients are at high risk for a variety of common symptoms, referral of large numbers is unrealistic, and the work lends itself to early and opportunistic interventions. An intervention is now available which can be delivered in a brief form and using it with affected adults is likely to have a positive impact on child health when there are also children in the family. This is, surely, a perfect example of good 'family medicine'.

The Alcohol, Drugs and the Family (ADF) Research Group: **Jim Orford, Alex Copello, Lorna Templeton, Richard Velleman, Akan Ibanga, and Ruchika Gajwani.** **We are grateful to Dr J.M.Wilkes, GP Special Interest in Substance Misuse, ISIS Project, London, for her helpful comments on a draft of this article.**

Further reading:

The 5-Step Method: a research-based programme of work to help family members affected by a relative's alcohol or drug misuse. The Alcohol, Drugs and the Family Research Group: Copello, A., Ibanga, A., Orford, J., Templeton, L. & Velleman, R. (2010). *Drugs: Education, Prevention & Policy*, 17(Supplement 1), 1-210.

Orford, J., Natera, G., Copello, A., Atkinson, C., Mora, J., Velleman, R., Crundall, I., Tiburcio, M., Templeton, L. and Walley, G. (2005a). *Coping with Alcohol and Drug Problems: The Experiences of Family Members in Three Contrasting Cultures.* London: Brunner-Routledge.

Julia Brown describes the important role primary care can play in the prevention and identification of foetal alcohol spectrum disorders. Ed.

Foetal alcohol spectrum disorders and the role of primary care

Like GPs, The FASD Trust finds itself in a position of both offering support to those affected by a condition, in our case, FASD (foetal alcohol spectrum disorders), as well as being on the front-line in terms of prevention, which is the main reason why I am pleased to have been asked to contribute this article.

Unfortunately many women - and many healthcare professionals - are still unclear about the potentially very damaging impact alcohol can have on a developing foetus, despite the 40 years of research we have available to us since the publication of Smith and Jones paper on Foetal Alcohol Syndrome in the Lancet in 1973[1], including the recently published research from the University of Oxford regarding moderate levels of alcohol in pregnancy having an impact on a child's IQ[2].

Pre-natal alcohol exposure not only affects the development of the foetal brain; it also impacts physically, with heart defects, eye and ear abnormalities and cleft palate being amongst the most common physical problems affecting those with FASD. These difficulties last a lifetime and the cost to society, at every level, is high. However, FASD is preventable if no alcohol is consumed during pregnancy.

GPs and their teams, including midwives and practice nurses, are in a unique position in terms of prevention of FASD, as in the majority of cases a GP is the first medical professional a pregnant woman will see. Indeed, she might even consult the GP or practice nurse prior to a planned pregnancy. At such appointments an opportunity is presented to talk to the patient about not consuming alcohol during their pregnancy. The FASD Trust has produced a practical, non-threatening leaflet, *Pregnancy and Alcohol* [3] used by many midwives and GPs. Medical professionals have reported that this leaflet is a useful tool to engage in a discussion with the patient about the potential risks of drinking alcohol when pregnant.

In 2007, the BMA produced a report [4] on FASD and made recommendations in terms of prevention, research, potential NHS referral pathways and clinical management of FASD. Following on from that, in February 2013 The FASD Trust will publish the proceedings outcome from the inaugural meeting of The FASD Trust's UK Medical & Healthcare Professionals Forum held in October 2011. This forum drew together, for the first time in the UK, a large multi-disciplinary group of medical professionals and over the last year this has developed into a final report, "Consensus Statement Regarding the Recognition and Diagnosis of Foetal Alcohol Spectrum Disorders Across the Lifespan in the UK: Recommendations for Clinical Practice" [5].

> *"GPs and their teams, including midwives and practice nurses, are in a unique position in terms of prevention of FASD, as in the majority of cases a GP is the first medical professional a pregnant woman will see"*

Over the last 40 years the UK has lagged behind the rest of the world, as in particular the Americans and the Canadians have led the way in recognising and managing FASD. The Consensus Statement is the start of that situation changing, particularly the complex issue of supporting those affected by FASD.

In respect of support, again the GP is normally the first port of call for those affected, and usually it is an anxious parent or carer who will be in your surgery. In fact, for many UK parents and carers the support offered by their GP has been invaluable.

Two of the key known protective factors in terms of those affected by FASD are *early diagnosis* and *intervention*[6]. GPs and health visitors can play an important role here in the early recognition of FASD symptoms in a baby or young child. Additionally, many health visitors now play a role in the health care checks for children in the care system and we know that the incidence rate of FASD amongst looked after children (including adopted children) is higher than in the general population. One of the issues addressed in the Consensus Statement and Clinical Guidance is referral pathways for those with FASD and where additional help can be sought by the GP for their patient.

In the absence of any concrete data in the UK, we rely on the World Health Organisation for prevalence rates; international studies point to a prevalence rate of 1 in 100. Therefore, it is good news that we are, as a medical profession here in the UK, starting to seriously address this major public health issue, to consider how we can have world-class clinical support for those affected and how we can significantly reduce the incidence rates by pro-active prevention work, especially amongst those identified as being at high risk of having a child affected by FASD.

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1 RECOGNITION OF THE FETAL ALCOHOL SYNDROME IN EARLY INFANCY - Kenneth L Jones and David W Smith, The Lancet, Volume 302, 3 November 1973.

2 Fetal Alcohol Exposure and IQ at Age 8: Evidence from a Population-Based Birth-Cohort Study – S J Lewis, M Barrow, R Gray, et al, November 2012

3 "Pregnancy and Alcohol" leaflets can be ordered from The FASD Trust, E: admin@fasdtrust.co.uk

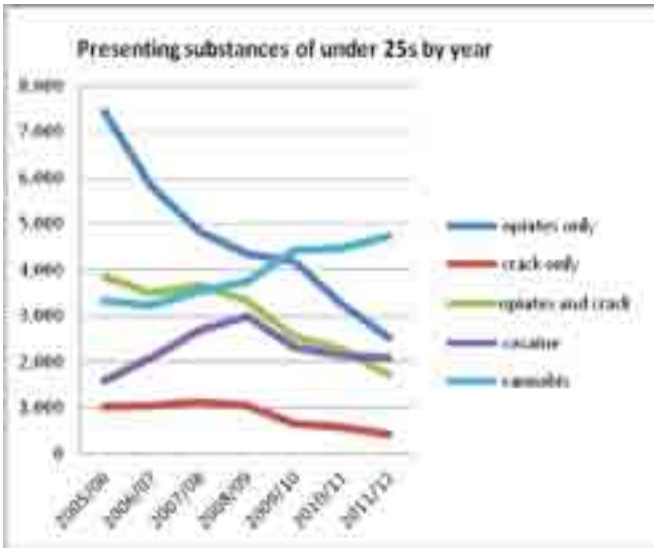
4 Foetal Alcohol Spectrum Disorders: A Guide for Healthcare Professionals - British Medical Association Board of Science, June 2007

5 The Consensus Statement and Forum Details, including Membership Applications, can be obtained from the website, www.fasdtrust.co.uk or by e-mail from Stefan Lang, Administrator, at events@fasdtrust.co.uk.

6 Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) - Ann P. Streissguth, Helen M. Barr, Julia Kogan, and Fred L. Bookstein, report to the Centers for Disease Control and Prevention, August 1996. (Ann Streissguth, Fetal Alcohol and Drug Unit, University of Washington School of Medicine, Seattle, USA)

Jonathan Knight takes us through the role of the National Drug Treatment Monitoring System over the years, including some insight into primary care data. Ed.

The National Drug Treatment Monitoring System – the numbers behind treatment delivery



As the National Treatment Agency (NTA) prepares to move to Public Health England, one of the NTA's most impressive achievements is the design and implementation of the National Drug Treatment Monitoring System (NDTMS).

The system began in 2004 and since then progress has been significant. With the hard work of keyworkers, support staff, service managers and of course the regional NDTMS teams we now have arguably one of the most robust, comprehensive and well utilised health data systems in the country.

NDTMS has expanded to collect information about both adults and young people receiving drug and alcohol treatment, from about 1,600 providers. These include community based, residential, criminal justice settings and GPs - the latter make up about 10% of all data returns.

The development of robust data was one factor which contributed to Government significantly increasing central funding for drug treatment. Similarly good data and demonstrable outcomes will support local areas to commission appropriate services in the future.

It has always been the NTA's goal to maximise the wealth of information we have. We achieve this via the wide-ranging set of reports that are regularly provided to local authorities and treatment agencies. These materials support: performance and outcomes improvement, service planning and strategic needs assessment. For the general public, stakeholders and media, treatment data is the basis for wider reporting and commentary to explain the trends.

NDTMS data also provides insight into the significant changes that have been seen in the treatment system over the last seven years, as well as in patterns of drug use in England more generally. Overall prevalence of opiate and / or crack use (OCU) has fallen since the estimates started in 2004/5 - from about 330,000 to just over 300,000 in 2009/10, with the biggest decreases occurring amongst younger age groups.

The annual adult treatment statistics are now following a similar trend. Following a peak in 2008/09, numbers are starting to fall. A lot of this is due to a decrease in those needing treatment in the first place. Just as importantly it will also be driven by the three fold increase in those successfully completing free of dependency each year (from 11,000 in 2005/06 to nearly 30,000 in 2011/12).

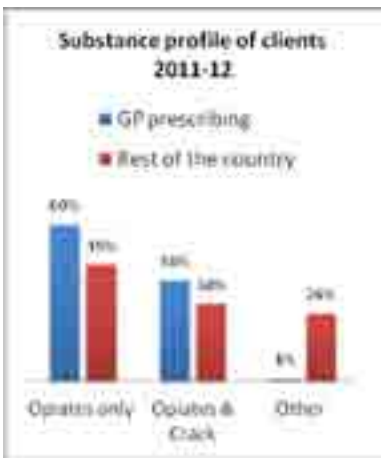
The largest reductions and most dramatic shifts in patterns of use have been seen amongst the under 25 age group. The overall number of presentations amongst this group has fallen by nearly six thousand since 2005/06, and the number of opiate and crack presentations is down two thirds over this time. Conversely there has been an increase in the number of clients over 40 presenting to treatment since 2005/06.

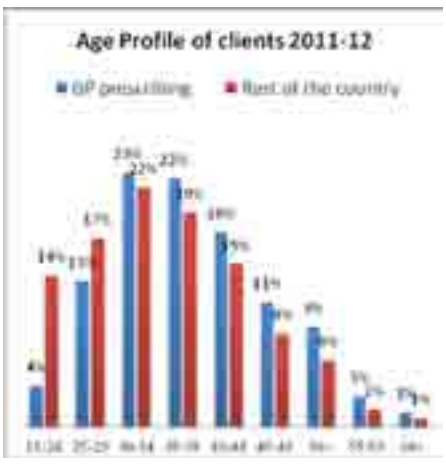
The declining trends in overall new presentations reflect falling prevalence of opiate and crack use, particularly amongst younger adult users. The numbers of new opiate users has fallen significantly and steadily since 2005/06, with 2011/12 seeing less than 10,000 coming into treatment for the first time.

While the treatment system is still overwhelmingly populated by OCUs and is likely to remain that way for some time, it will also have to be able to respond to new types of problems. The needs of an aging cohort of clients that have been using opiates and crack for a significant length of time present another significant challenge.

This is particularly apparent in relation to clients that are recorded on NDTMS as being either in shared care or receiving prescribing treatment solely from a GP. Nearly 100% of them are users of opiates only or opiates and crack and they tend to be older than the general treatment population, with over 40% being over 40 and a very small proportion being under 25.

As well as highlighting trends NDTMS can be used to identify which recovery factors enhance treatment outcomes. For





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example, data collected through the Treatment Outcomes Profile (TOP) shows that opiate clients - (most of who will be in receipt of substitute prescribing) - are five to ten times more likely to leave successfully if they can achieve abstinence from illicit use of opiates, often alongside their use of substitute medication.

But abstinence alone is not always enough, and stable housing together with employment are important factors too; 46% of opiate clients that achieved all three at six months successfully completed within three years of starting treatment, compared to 15% of those that had not.

NDTMS, like the treatment system, needs to adapt with the times. It has recently seen the biggest changes since its inception with the implementation of core dataset J which, by introducing new recovery intervention types, setting and time in treatment, leaves it in great shape for Public Health England to take on.

To find out more about NDTMS data, or how the information is used, here are some useful links -

https://www.ndtms.net/

http://www.nta.nhs.uk/ndtms.aspx

Jonathan Knight, NTA Analysis Manager

Paul Hayes, outgoing Chief Executive Officer of the National Treatment Agency, gives his account of the history of drug treatment, spanning the Thatcher years to the end of the New Labour era. His unique position gives some fascinating insights into the subject. Ed.

A brief history of drug treatment policy 1979-2010

History is more an argument than a record. This is my history, reflecting my experience, viewed from my perspective. It is "a" history, rather than "the" history.

Prologue

The 1960s and 70s had seen a dramatic growth in drug use on the back of the burgeoning youth culture, expanding disposable incomes and globalisation. Particular youth sub-cultures were associated with different drugs; mods with amphetamines, wannabe hippies with LSD but overwhelmingly "drugs" meant cannabis. As cannabis use spread amongst middle class youth with limited discernable impact it became impossible to characterise its use as a direct threat to social order and concern focused instead on its potential as a gateway to heroin. Historically, heroin use had been restricted to tiny segments of society; medics (because of availability) and risk seeking bohemians and socialites. Since the 1920s the clinical response had been based on maintenance prescribing of opiates, but increasing use during the late 1960s, allied to concern about leakage from private doctors into the illicit market resulted in a new approach. Treatment became concentrated in a small number of Drug Dependency Units, led by psychiatrists prescribing methadone rather than diamorphine and focussed on achieving abstinence through gradually reducing doses, routinely excluding patients who continued to use on top of their script or who missed appointments. The number of addicts remained small and the focus of policy was to address the health and social consequences of individuals' addiction.

> *"Smokeable heroin began to access the UK market at exactly the time that the economic policies of the Thatcher government were leading to the deindustrialisation of the North and the Midlands"*

Thatcher

In 1979 official statistics recorded fewer than 3,000 heroin addicts in England, the vast majority in London, focused like other parts of the demimonde on the West End. By 1998 there were 85,000 in treatment across the whole country, concentrated in council estates in Liverpool, Manchester and South London with another 100,000 excluded from treatment by waiting times of many months. Two facts came together to generate this explosion. Smokeable heroin began to access the UK market at exactly the time that the economic policies of the Thatcher government were leading to the deindustrialisation of the North and the Midlands. A generation who left school expecting to work in local economies dominated by manufacturing, docks, shipyards and mines were excluded from the labour market, and held in a protracted adolescence lacking responsibility, respect and hope. This particularly vulnerable generation was the first to be exposed to readily accessible, relatively cheap, smokeable heroin, and a significant minority became drawn-in to ***chasing the dragon***. Heroin use was so closely connected to injection in the popular consciousness that the risks associated with smoking the drug were little understood. As dependence took hold increasing numbers of smokers began to shift to injecting as a much more efficient and cost effective route of administration.

Tragically this coincided with the arrival of the AIDS epidemic in the UK adding dramatically to the risks associated with injecting drug use, particularly amongst a population of naïve users in close social networks without access to supplies of clean needles and syringes.

Responding to this crisis the Advisory Council on the Misuse of Drugs (ACMD) published two reports on AIDS and Drug Misuse which concluded that HIV was a bigger threat to public health than drug misuse and practice needed to be comprehensively realigned to reflect this.

Three major changes were initiated. The Department of Health (DH) made money available for a network of needle and syringe exchanges across the country. The Drug Dependency Units lost their monopoly as Community Drug Teams were established with much broader geographic coverage often working in tandem with GPs in shared care arrangements. The focus of practice moved from abstinence to maintenance with an emphasis on the potential for long term prescribing to reduce overall use of heroin and rates of injection rather than the ***abstinence or exclusion*** approach of previous regimes.

This clinically-led shift in policy was strongly supported by Norman Fowler as Secretary of State for Health who was able to draw on the sense of national public health crisis created by the AIDS epidemic, and the political air cover given to him by Margaret Thatcher's impeccable socially conservative credentials to protect him from political and media attack.

Major

Norman Fowler's bravery in embracing harm reduction and Margaret Thatcher's wisdom in providing him the space to do so is brought into sharp relief by the subsequent struggles of the Major government.

The undoubted public health success of the harm reduction approach left England with some of the lowest rates of HIV infection in the world and helped abate the crisis. Perhaps predictably as the sense of national emergency receded doubts about the morality of condoning drug use, which is inherent in the pragmatism of harm reduction, resurfaced. At first there was no overt attempt to return to previous practice but in 1994 Brian Mawhinney, the responsible Health Minister, established a Task Force to determine if the clinical benefit of harm reduction justified the moral compromise involved. A senior Church of England academic chaired the enquiry symbolising that moral issues were as significant as clinical. To inform the process the National Treatment Outcome Research Study (NTORS) was established, the largest study into the effectiveness of treatment yet attempted.

In the meantime the Government's 1995 strategy used judicious language to enable harm reduction and maintenance prescribing to continue but fell well short of openly endorsing the approach. The Task Force reported in 1996 drawing on international evidence and the early findings from NTORS to emphatically endorse both harm reduction and maintenance prescribing. This then fed into the formal purchasing guidance issued by DH to Health Authorities in April 1997.

The public health success of the harm reduction approach reduced the threat from HIV to such an extent that as the crisis receded priorities were revisited. The overrepresentation of offenders amongst injecting drug users had forced the NHS to prioritise access to services for what had historically been an underserved population. Although health investment in pursuit of public health gain had been the motivation for these initiatives the police very quickly came to value the reduction in acquisitive crime that accompanied treatment engagement. The Home

Office began to invest its own resources in establishing Arrest Referral Schemes linking offenders into treatment from police stations and the Criminal Justice Act 1991 contained provision to mandate treatment as part of a sentence[1].

> ***"The undoubted public health success of the harm reduction approach left England with some of the lowest rates of HIV infection in the world"***

The growing significance of the criminal justice system in treatment was recognised when as part of the 1995 Drug Strategy, local Drug Action Teams (DATs) were established in every top tier local authority to take strategic control of local effort to prevent supply, promote prevention, and provide treatment. Each local area was obliged to establish a DAT comprising of (as core membership) Local Authorities, local NHS, police and probation. National leadership came from Tony Newton in the Cabinet Office to reflect the cross-cutting nature of the issue.

Meanwhile patterns of use were shifting to intensify the challenge. Overall drug use and drug related crime continued to increase, as did overdose deaths. Crack became embedded in UK drug culture giving rise to concerns that this would create a new epidemic with dramatic impact on social cohesion and crime, particularly within black communities. Although the binge nature of the drug's use (and its associated criminality) had dramatic consequences for individuals, the impact on society at large was limited as the population most vulnerable to crack addiction were those people already vulnerable to heroin. The number of new addicts was therefore much lower than policy makers had feared.

The Major government consolidated the centrality of harm reduction to practice, began the development of dedicated routes into treatment for offenders and by creating DATs established the structure that would successfully blend local ownership and national resources for the following seventeen years. However although the foundation of the future shape of policy and practice had been set, resources were not yet available to capitalise on this.

Blair

Committed to Ken Clarke's spending plans, the incoming government's room for manoeuvre was limited. Political leadership for drug policy remained in Cabinet Office but a new role of National Anti-Drug Co-ordinator (Drug Czar) was created and given to Keith Halliwell, previously Chief Constable of West Yorkshire. This was designed to give reassurance to

1 The Act gave courts power to mandate treatment but no capacity to pay for it, as the Home Office had failed to understand the consequences of the emerging purchaser/provider split in the NHS. Not surprisingly very few orders were made.

middle England that New Labour would not be soft on drugs and emphasised the growing priority being given to the drug/crime link. As Shadow Home Secretary, Blair had coined "tough on crime, tough on the causes of crime", and Labour had committed itself to breaking the cycle of addiction, crime and imprisonment through access to treatment enforced by a court and piloted Drug Treatment and Testing Orders during the first term to test the proposition.

The new government's 1998 Drug Strategy focussed, as had its predecessors, on supply, prevention and treatment but by the start of the second term it had become clear that investment in supply reduction offered poor value for money, prevention lacked a credible evidence base and the only demonstrably effective levers were in the treatment strand of the strategy.

Unfortunately drug treatment was a DH responsibility and was not accorded a high priority by either DH or local health authorities. The rapid expansion of heroin and crack addiction had not been matched by increasing investment. Some of the local areas hardest hit had increased services but in many other areas local priorities squeezed out drug treatment to the detriment not only of drug users but also of local criminal justice agencies and the communities they served as drug-related crime escalated.

Having demonstrated prudence in the first term, the government went into the 2001 election with ambitious spending plans including dramatic growth in direct central government support for drug treatment, from £50m per year to £360m over the parliament. The explicit rationale for this was to invest in NHS commissioned and delivered treatment to yield a criminal justice benefit. The government had been persuaded, in particular by the evidence from the Major government's NTORS study, that increased access to treatment and reduced waiting times would significantly reduce crime. However there was no guarantee that left to its own devices the NHS would spend these resources on crime reducing drug treatment rather than its natural priorities. The solution was to create a cross-government entity, formally part of the NHS, but jointly accountable to DH and Home Office Ministers; the National Treatment Agency (NTA), and give it responsibility for overseeing a separately badged strand of health funding: the Pooled Treatment Budget (PTB).

The crime reduction focus of the NTA was emphasised by the appointment of a Chief Probation Officer as its Chief Executive Officer and representation of the Prison Service and Youth Justice Board as well as the Home Office on the Board. Despite initial resistance from DH, the NHS and the professions, the criminal justice agenda expanded. The Drug Intervention Project (DIP) was established in 2002 to provide rapid dedicated routes into treatment for all offenders, joint targets were agreed with the Youth Justice Board and the NTA eventually assumed responsibility for treatment in prison.

The NTA required each DAT to establish dedicated commissioning capacity to oversee the new resources which would grow to £750m a year by 2010. Most of the new capacity created was delivered by the voluntary sector who offered better value for money, more flexibility, and a greater willingness to embrace the criminal justice focus than the traditional NHS providers.

With crime reduction now at the centre of the policy, formal leadership passed from the Cabinet Office and the Czar to the Home Office under David Blunkett. In typical New Labour fashion the additional investment was accompanied by targets and a process of accountability overseen by the newly established Prime Minister's Delivery Unit. Quarterly stocktakes on progress towards targets were chaired by the Prime Minister which signalled the political significance of drug policy in general and the potential for treatment to reduce crime in particular to the whole government.

> ***"The funding and target regimes rewarded commissioners for access and retention not treatment completion or long term outcomes"***

The combined impact of the additional investment, performance management of targets supported by the National Drug Treatment Monitoring System, dedicated commissioning capacity, and strong political support was to dramatically improve the availability and quality of treatment. The number of adults in treatment more than doubled to over 200,000. Over 60% of England's heroin users were benefitting from treatment, compared to 30% in the US and 12% in France. Waiting times fell from an average 12 weeks to 5 days. Drug related crime was reduced, and made a significant contribution to the overall reduction in crime that had begun when Michael Howard was Home Secretary and accelerated during the Blair years. Drug-related deaths stabilised after many years of increase and the level of blood borne virus infections amongst the English drug addicted population was held at much lower levels than most of Western Europe and North America.

The additional resources levered in by embracing the Government's crime reduction agenda had benefitted not just offenders but all service users. As clinicians recognised the potential benefit for the entire system the initial resistance to criminal justice engagement began to soften.

By 2005 enough had been achieved for the government to go into the election pledging still more investment in treatment, and for the NTA to begin to shift its emphasis from access and retention to completion and discharge. The vehicle for this was the Treatment Effectiveness Strategy (TES) launched by the Prime Minister in Alan Milburn's Darlington constituency which challenged commissioners and clinicians to be more ambitious for their service users to use treatment to overcome dependency and become fully functioning citizens.

The TES failed to gain traction and made little real impact on delivery which continued to be focussed on access and retention. There was too little incentive for the system to shift from its maintenance prescribing paradigm. Clinicians valued maintenance prescribing for saving lives, the police valued reduced crime. The funding and target regimes rewarded commissioners for access and retention not treatment completion or long term outcomes. As is inevitable in government, the success of treatment in reducing crime moved it down the political priorities weakening levers for further change, a process which accelerated as Iraq and terrorism dominated the Number 10 and Home Office agenda.

Crucially there was little support from service users for the TES. Achieving abstinence and leaving a supportive, stable treatment regime to ***take life neat*** is challenging and scary. The

dramatic growth in treatment meant many service users were still benefiting from replacing chaos with stability and were not yet ready to move on. Furthermore the TES was pitched as a top down response to a bureaucratic problem: "how can we stop the system silting up without limitless investment?", rather than focussing on the aspirations of service users.

The Blair era therefore finished with the drug treatment system having delivered what was asked of it in 2001, but having failed to grasp the opportunities this success opened up.

Brown

Although always contentious, drug policy had not previously been a party political battleground. That changed in 2006/07 as the work of the Centre for Social Justice identified addiction as one of the root causes of the "broken society", and critiqued the Labour government's policy as "state sponsored drug dealing"[2]. Maintenance prescribing was characterised as a barrier to "full recovery" for individuals and a device by which the NHS had squeezed out voluntary sector delivered residential services focussed on abstinence. The emphasis on crime reduction was held responsible for under investment in cannabis and alcohol treatment. Targets, financial incentives and the NTA were described as statist, bureaucratic impositions which inhibited practitioners from meeting service users' needs and delivering sustainable outcomes.

This critique resonated with a small minority of voluntary sector providers who had failed to compete in the market place as the system had expanded and who began to lobby Conservative politicians as the government in waiting. An ideological schism opened up in the sector between abstinence and maintenance, factions which played out in the media in a series of stories about the "failure" of the treatment system to "cure" more than 3% of patients.

Although the statistics were spurious and much of the polemic was driven by provider self-interest, the critique was not without substance. Stripped of the rhetoric the treatment system had a case to answer that it was still too prepared to allow individuals to remain in treatment for many years with little or no effort to help/ persuade/ cajole them to move on. There was legitimate concern that the rapid growth of the system had led to an underdeveloped, under skilled, and under supported workforce, unable to engage service users in real change.

Sustained political and media challenge revitalised ministerial and number 10 interest in treatment as the 10 year 1998 Drug Strategy came to the end of its life. The 2008 strategy emphasised the successes of treatment over the past decade rejecting the ideological critique of maintenance prescribing and defending the prioritisation of criminal justice outcomes. Crucially however it also accepted that the next challenge for the treatment system was to enable more people to leave treatment having overcome addiction, earn their own living, maintain their own home and make a positive contribution to society. Preventing harm and reducing crime were no longer enough.

This failed to satisfy the government's critics who demanded an explicit commitment to abstinence, and increased funding for residential rehabilitation. However it provided an opportunity for the NTA to revisit its 2005 agenda, this time with more success.

Over the next two years financial incentives for successful completions were added to the PTB allocation formula. A Skills Consortium was created, jointly owned by all providers and educators to drive up skill levels. Joint work was initiated with the Department for Work and Pensions to route treatment graduates into work and relevant claimants into treatment. Treatment in prison was put on a level footing with community treatment and continuity of care improved.

All of this combined to significantly increase the number of people successfully completing treatment year on year [3].

> ***"An ideological schism opened up in the sector between abstinence and maintenance, factions which played out in the media in a series of stories about the "failure" of the treatment system to "cure" more than 3% of patients"***

Winning the hearts and minds of practitioners for the new agenda was initially less successful. The politicisation of treatment and the impending election resulted in police disengagement at a national level. Clinicians, feeling themselves safe behind clinical autonomy and National Institute for Clinical Excellence endorsed evidence based practice, continued to resist challenges to their ***safety first*** practice. This was particularly true of many GPs, whose day job is to manage life long conditions and who resented practice which they saw as life saving being dismissed as ***parking on methadone***.

However the ground was shifting under everyone's feet as the service user voice began to be heard. Attempts to end the ideological schism within the sector by agreeing an inclusive definition of recovery continued to flounder but a consensus began to coalesce around a model of recovery that emphasised individual choice, ambition tempered with realistic caution, the added value of mutual aid, and the potential for maintenance prescribing to be a bridge to long term recovery. It would fall to the incoming government to try to shape this emerging consensus into a coherent strategy.

Paul Hayes, National Treatment Agency Chief Executive

2 Carefully airbrushing the Thatcher and Major governments' role out of history

3 Between 2008 and 2011 33% of new treatment entrants successfully completed and did not return

Gill Burns suggests that the current enhanced service contracts are out of date, and we need to act now to protect investment in primary care drug and alcohol treatment. Ed.

How do we protect investment in primary care for drug and alcohol treatment for the future?

It is often said that "there is no such thing as a free lunch" and following a working lunch with a few members of SMMGP I found myself committed to writing an article for Network newsletter! I have worked in the field in a variety of roles for over 18 years including clinical and managerial roles, currently managing the commissioning and performance of drug and alcohol contracts in primary care, referred to as "Shared Care", and felt that writing an article for Network was an opportunity to get people thinking about the future role of primary care in the treatment of substance misuse.

There have been many investments and enhancements to the treatment sector leading to improvements for both patients and staff over the years including the contracting of GPs in many areas to provide enhanced services. However, as I am sure none of us have failed to notice, things are changing and there is much uncertainty around the future commissioning of drug and alcohol treatment services.

A number of national drivers and agendas including new primary care commissioning arrangements combine to make this a unique time for the drug and alcohol treatment sector. As stated by Paul Hayes in an article for Network newsletter last year, "It is not a time to rest on our laurels". April will see the new public health bodies in local councils taking responsibility for commissioning drug and alcohol services, with the removal of ring fenced budgets. The 2010 Drug Strategy emphasises recovery and re-integration[1]. The National Treatment Agency's recent Recovery Oriented Drug Treatment Expert Group set some challenges for the sector in moving forward, not least for primary care and how it must embrace the recovery agenda and examine current prescribing of substitution therapies. Recently, the news headlines have included articles on the re-emerging theme of legalising drugs. In addition to this we have the stigmatisation of methadone treatment in the media.

The future feels uncertain and one of the biggest areas of concern is the arrangements for commissioning of primary care enhanced services. These exist in many areas of the country varying in size and capacity; all providing prescribing for drug dependent patients who require some form of opiate substitution therapy as part of their treatment. Some areas also include enhanced services in primary care for alcohol dependent patients, but my sense is that this is less common.

Many areas of the country appear to be in a holding position until the end of the next financial year, but should we be getting the primary care house in order now to be ready to rise to the challenge? And if so, how do we protect the levels of investment that have been funded to date to support the sustainment and on-going development of primary care based services and encourage future investment?

First, we need a re-branding exercise which is something which has been muted for the last few years. "Shared care" is a vague term which does not explain adequately the work of GPs and others. It does not reflect delivery, performance, accountability and governance which are fundamental elements of a robust contract. If we want to provide treatment for patients who have drug and alcohol dependency in primary care, then why not refer to it as that? Primary Care Based Drug and Alcohol Treatment Services!

> ***"The future feels uncertain and one of the biggest areas of concern is the arrangements for commissioning of primary care enhanced services"***

Second, primary care has not traditionally been very good at demonstrating effectiveness, performance or the range of additional health interventions that it provides. Recently we have seen some negative publicity implying that it is GPs that park patients on methadone. In drug treatment, emphasis has historically been placed on increasing the numbers in treatment as opposed to defining the extent and range of treatments that are provided and the evidencing of success. Enhanced service contracts urgently need to be revised and rewritten with robust block contracts, with smaller numbers of keen and enthusiastic GPs who are committed to the drug and alcohol agenda both clinically and politically providing safe and effective substance misuse services. Costs should be clear from the outset based on defined clinical interventions and outcomes with simplified payment systems for comprehensive treatment packages. Audit, review and reporting must be built into the core contract with mechanisms to address poor performance including stipulation of minimum standards around training, competencies and continuing professional development. Contracts may be with individual practices or groups of practices with specialist GPs identified to manage patients with the appropriate liaison and support from other relevant drug treatment agencies.

What primary care can offer needs to be clearly articulated. A selling point is the role of GPs with alcohol dependent patients. Many lower level alcohol dependent patients, refusing to attend alcohol services, are managed in primary care. This valuable resource could be added to a primary care package. Drug and alcohol treatment could therefore be combined in one contract with a defined range of interventions appropriate to the setting.

We need to focus on what is already provided and emphasise the positives. Primary care exists within local accessible premises, a non-stigmatising environment with flexible opening hours. There is comprehensive information technology in the form of medical computer systems, and specific drug and alcohol templates alongside a range of other health templates to guide and record health checks and activity. GPs are often described as the bedrock of healthcare and already see complex patients on a regular basis including those with mental health problems, dual diagnosis and long term health conditions. We know that there are an increasing number of ageing patients in the treatment system with increasingly complex health problems. GPs are well placed to treat these complexities and already provide treatment

1 HM Government (2010) Drug strategy 2010: reducing demand, restricting supply, building recovery: supporting people to live a drug-free life

for health issues such as chronic obstructive pulmonary disease, sexual health issues, and screening for blood borne viruses and alcohol misuse. There are newer drug related problems including the emerging club drug and legal drug scene. Many patients attend their GPs as an acceptable treatment option as opposed to the local drug services which have been traditionally associated with injecting drug users.

Primary care treatment packages need to have the additional supports to meet the recovery and re-integration agenda with psycho-social interventions provided including access to group therapy and alternative supports such as residential detoxification and rehabilitation. GPs have to grasp and evidence the concept of recovery and detail how this can be facilitated in enhanced service contracts. There are already some models supporting this work across the country.

At a recent GP training event held locally, two service users gave an account of their experiences of treatment. Both eloquently articulated how they had been in treatment for in excess of 20 years but were now both in recovery. Without prompt or encouragement, they both independently outlined in an honest and thought provoking way how positively they had been treated by their respective GPs; when there were no drug treatment services, when services were de-commissioned and re-commissioned and key workers changed regularly, the only constant health professional in their lengthy treatment journey was their GP. Their testimony was a very powerful message around the tragedy for patients if drug and alcohol treatment were to be removed from the primary care system.

"Enhanced service contracts urgently need to be revised and rewritten"

Enhanced services in primary care need to evidence that they are fit for purpose to protect investment for the future. To achieve this we need dedicated leadership and management to shape primary care services and strong communication with commissioners including clinical commissioning groups, public health and health and wellbeing boards to argue for treatment packages for drug and alcohol patients that can be delivered in primary care.

Gill Burns, Manager of Primary Care Drug and Alcohol Services NHS East London and the City

Chris Ford outlines the effect of unhealthy drug policies and argues that doctors have an important role in shaping and influencing a healthier approach to drug policy. Ed.

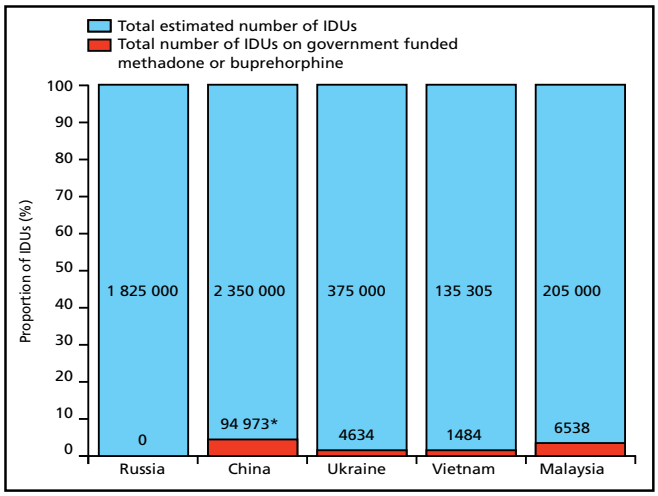
What effect drug policy has on treatment and why we need to be involved

I was enjoying chatting to an enthusiastic GP Registrar who had recently completed the Royal College of General Practitioners Management of Drug Misuse Part 1 when he asked me why I had become involved in drug policy and could it really affect treatment? I thought it was such an important question that I would try and answer it for Network.

What is drug policy?

It's a system of laws, regulatory measures, courses of action and funding priorities concerning all activities related to illicit drugs and promulgated by a governmental entity or its representatives. It involves a set of principles or an ideology that directs public action in this field (for example a 'war on drugs', or a 'harm reduction' approach).

We know the global war on drugs has failed and this has had devastating consequences for individuals and communities around the world. Large amounts of money have been spent on criminalisation and repressive measures have failed to curtail supply or consumption. But these repressive efforts have harmed people who use drugs and impeded progress on public health measures: to reduce HIV and hepatitis C; provide accessible opioid substitute therapy; and prevent other harm reduction measures to be available to all who need them. Drug policy is being used by many countries to justify individuals' and governments' moralistic and prejudiced opinions.



Opioid substitute therapy available to less than 2% of injecting drug users

Source: **The Lancet : HIV in people who use drugs "Treatment and care for injecting drug users with HIV infection: a review of barriers and ways forward."** ***Wolfe, D; Carriere, P; Shepard, D.*** ***The Lancet July 2010; 376:355-366***

Because of this people who use drugs are often stigmatised and are not treated in the same way as other patients - why? Is it to do with illegality? Is it a moral judgement? Why are so many countries allowed to get away with punishing people who use drugs rather than supporting them? In this era of evidence-based practice why is the evidence we have in the drugs field, both in clinical practice and policy, not used?

What do we know?

1. Is the HIV epidemic fuelled by bad drug policy and the war on drugs? Yes
    a. In Russia 37% of the 1.8 million people who inject drugs are infected with HIV, where needle and syringe

...continued overleaf

provision is severely limited and opioid substitution therapy is illegal[1].

b. In countries with long- established harm reduction programs, such as the UK, Australia and Germany, HIV rates are below 5%[2].

c. In Vietnam 44% of HIV is in people who inject but they only make up 6.3% of the patients receiving antiretroviral therapy[2].

2. Does more humane policy affect the amount of drug use? No and to quote the World Health Organisation
"Globally, drug use is not distributed evenly and is not simply related to drug policy, since countries with stringent user-level illegal drug policies did not have lower levels of use than countries with liberal ones."[3]
3. Is the war on drugs working? No, it has failed and it is in fact a war on people. To quote Mexican poet, Javier Sicilia who lost his son in the cross fire of Mexico's drug war: *"The politicians are formulating the drug problem as an issue of national security, but it is an issue of public health"*
We must consider decriminalisation to avoid patients with a health problem becoming criminals.
4. What do we know from the results of International Doctors for Healthy Drug Policy (IDHDP) questionnaire to its members in over 50 countries, on how the medical treatment of people who use drugs was affected by their country's drug policy?
   a. Results showed that all countries' drug treatment systems were affected by their national drug policy, mostly in a negative way, particularly with regards to health and rates of HIV infection, where policies worked against evidence-based medical treatment.
   b. Many countries reported similar issues with the impact of stigma, interference by law enforcement and how a change in government interrupts progress in putting policy into practice.
5. Do drug detention centres stop people using drugs? No!
   a. Over 40 states apply some type of judicial corporal punishment for drug and alcohol offences and call it treatment but people have no right of appeal, are exposed to forced labour and receive no treatment [4].

And I could go on but the sum of the evidence is that unhealthy drug policies are bad for people's health.

So what evidence do we have that healthy drug policies improve health?

Lots! For me a healthy drug policy is one which consists of a balanced and integrated whole system including; prevention, controls on supply, good evidence based treatment, with choice, for all who request it, placing them firmly at the centre. Systems which work are those that meet needs and comply with evidence rather than those based on opinion, and which are subject to regular review and evaluation.

Look at Switzerland, which introduced an integrated healthy drug policy in the late 1980s, and found that: between 1991 and 2004, drug related deaths declined by more than 50%; levels of new HIV infections divided by 8 within 10 years; there was a 90% reduction of property crime committed by drug users; and 70% of injectors are now in some kind of treatment [5].

Or Portugal who, shocked at their HIV rate in injectors, introduced an integrated drug policy including decriminalisation and found: the number of street overdoses fell from 400 to 290 annually; there has been reduced illicit drug use among the most at-risk group (15-19 year olds) since 2003; and there has been reduced prevalence of HIV among injecting drug users and an expansion of numbers in treatment [6].

So I'm hoping I have begun to answer the registrar's question and that he and indeed all doctors will join IDHDP as we aim to mobilise the voice and increase the participation of doctors in drug policy reforms, which has been sadly lacking for too long, by building a bridge from health to policies; treating people who use drugs problematically with respect and with evidence based treatments; preventing the spread of HIV, hepatitis C, hepatitis B and tuberculosis and other infectious diseases and fatal overdoses by providing new needles and syringes, opioid substitution treatment, overdose prevention training and naloxone, condoms and safer injecting facilities to all who need and want them; and using our knowledge of what works in clinical practice to influence (or change) drug policies.

Drug policy is particularly vulnerable to political influence that has little to do with evidence-based medicine, probably more so than any other area of health, and it is important to identify this and challenge where it is happening.

At the moment IDHDP membership is only open to doctors but all other practitioners are invited to join the IDHDP forums and can receive our monthly updates. Go to www.idhdp.com for more information.

What does this mean for UK?

I feel we have often been preoccupied by the wrong things, concentrating on crime reduction rather than health improvement, lurching from retention (rather than improvements) to completions (and out of treatment). We have often been distracted by cheapness rather than quality, "drug misuse" rather than focusing on the person, and protecting the community rather than realising we are all part of the community, whether we use drugs or not. We need to balance aspiration with caution and what we need more than anything is a joined up integrated system based on evidence rather than opinion. We have come a long way in the last 10-15 years and we need to protect what we have improved and not be fearful of doing things even better.

Join the debate for improved drug policy in UK and beyond – the time for action is now.

Dr Chris Ford Clinical Director IDHDP chris.ford@idhdp.com
website: www.idhdp.com

1 Global Commission on Drug Policy's report, "The War on Drugs and HIV/AIDS: How the Criminalization of Drug Use Fuels the Global Pandemic," June 2012.

2 HIV in people who use drugs "Treatment and care for injecting drug users with HIV infection: a review of barriers and ways forward ." *Wolfe D et al., July Lancet 2010; 376: 35-366*)

3 Degenhard et al., World Health Organisation, 2008 'Toward a Global View of Alcohol, Tobacco, Cannabis, and Cocaine Use: Findings from the WHO World Mental Health Surveys' http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0050141

4 Inflicting Harm: Judicial corporal punishment for Drug and Alcohol Offences in Selected Countries. HRI *November 2011*

5 From the Mountaintops: What the World Can Learn from Drug Policy Change in Switzerland October 2010 by Joanne Csete Global Drug Policy Program

6 Drug Policy in Portugal: The Benefits of Decriminalizing Drug Use Artur Domostawski June 2011 Global Drug Policy Program

Euan Lawson is Dr Fixit to a doctor working with an alcohol dependent patient who is struggling to become abstinent. Ed.

Doctor Fixit on alcohol dependency

Dear Dr Fixit,

One of my patients is a 35-year-old man, Bob, who has been drinking heavily for many years. He has recently been through a community detoxification but he relapsed within a few weeks. I am increasingly worried about his physical condition - it has noticeably deteriorated recently. He doesn't appear hugely motivated to try again. I'd be grateful for some advice on how to manage him now.

Answer provided by
Dr Euan Lawson, GP.

The initial stages after a relapse can be a challenging time for everyone. It takes a lot of time and effort to organise a community detoxification and it's possible you may be feeling some frustration that the outcome isn't as good as you'd hoped. Bob and his family will also be going through a range of emotions. Sadness and anxiety for the future would be understandable; irritation, perhaps outright anger, may be expected as well.

It would usually be appropriate to sit down and do some one-to-one work with Bob first to try to establish the circumstances and triggers around the relapse. Bob's apparent lack of motivation could form part of a range of issues. It could be a reaction to the failure of the detoxification but perhaps his mood is low and there is some underlying depression. Clearly, treating this while he is still drinking is problematic but may be an important area to prioritise in the weeks following any further detoxification. Other mental health issues may need to be addressed. While it may be appropriate to plan for an immediate further detoxification it is common to give it a period of time to take stock. In addition, the phenomenon of kindling - where repeated detoxifications are associated with increased risk of complications during alcohol withdrawal - means that a re-assessment of the risks associated with another community detoxification would be justified.

Perhaps Bob would benefit from an inpatient detox with a period of rehabilitation? If not, there may be other resources that can be exploited for a further attempt - you might be able to access peer support or pre-detoxification groups in the run up to any further withdrawal. If relapse is a significant problem then further prescribing options may be warranted. Post-detox acamprosate and naltrexone have been shown in a recent meta-analysis to be effective at reducing relapse - with acamprosate just favoured.

Despite all the planning sometimes the next detoxification will come unexpectedly. The physical consequences of alcohol mean that acute admissions aren't uncommon and the hospital will often start the process of detoxification. It's worth making sure you are in a position to take advantage of these opportunities. It is common for people to be discharged before they have completed their detoxification and not all hospitals will take the time to ensure appropriate follow-up. This means that the individual will go straight back to drinking and another opportunity has been missed. If you can react quickly, with a review immediately on discharge, there may be an opportunity to complete the detoxification.

Other harm reduction measures should also be considered. Perhaps Bob's apparent lack of motivation may be an indicator of some cognitive deficit. Not all of these will be treatable but we know that Wernicke Korsakoff Syndrome (WKS) is under-diagnosed and under-treated. The prescription of thiamine is normal practice and may be particularly relevant for Bob. Most people know that oral absorption of thiamine isn't great but it should be continued and, even in primary care, there is nothing to stop you giving intramuscular doses if it's a significant concern. There should be resuscitation facilities - but the risk is no greater than that for immunisations. It may also be worth considering continuing with a medication like naltrexone even in those who do relapse to some drinking. Again, recent evidence has suggested that they can help reduce heavy drinking post-detox.

> ***"Despite all the efforts of the individual, their family, and the treatment services, not everyone will be able to stop in time to save them from the consequences of their alcohol use"***

Despite all the efforts of the individual, their family, and the treatment services, not everyone will be able to stop in time to save them from the consequences of their alcohol use. I recently had a young man in his 30s, who despite repeated detoxes, relapsed time and time again. He would sit in the clinic moist-eyed, puffy-faced, marked with naevi, and with an increasingly obvious yellow tinge. It was clear his liver was deeply damaged. He had oesophageal varices and the frequency of his hospital admissions was increasing ominously. Inevitably, he was admitted again with a severe bleed and we were able to visit him in hospital and contribute to the management of another detoxification.

The detox held and this young man enjoyed several weeks alcohol-free, clear-headed and sober. He didn't relapse again but within a few weeks he had another variceal bleed and he died. He knew how ill he was and, in truth, a detox in his case was verging on a palliative measure. We took some comfort, and we are sure he did, that his last days were sober. Clearly, recurrent detoxification failures and relapses can be frustrating for the team and for the clinicians. Sometimes palliation is all we have but even those with a dismal prognosis can be offered treatment, even detoxification, as part of their end of life care.

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